Transfusion-free treatment of Jehovah's Witnesses: respecting the autonomous patient's rights

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Abstract

Do six million Jehovah's Witnesses mean what they say? Muramoto's not-so-subtle proposition is that they don't, because of a system of control akin to the Orwellian "thought police". My response is that the fast developing cooperative relationship between our worldwide community and the medical profession as a whole, and the proven record of that community's steadfast integrity in relation to their Christian principles is the evidence that we do! I seek to highlight the inaccuracy of information, which Muramoto admits came largely from dis-enchanted ex-members, by quoting "established" medical ethical opinion that refusal of blood transfusions must be respected as evidence of patient autonomy. Personal experience of my work on hospital liaison committees for Jehovah's Witnesses is reviewed and I endeavour to prove that our view of blood, and its association with life, goes to the very core of the human psyche. Lastly I suggest that faith transcends rationality. Human beings are more than just minds! Our deep moral sense and consciousness that our dignity is diminished by living our lives solely on the "self interest" principle, lies at the heart of true personal autonomy. Maybe it's a case of "two men looking through the same bars: one seeing mud, the other stars",1

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Introduction

Articles in the columns of this journal have sought to investigate the boundaries of informed rational, patient decision making. Jehovah's Witnesses have often been used as the classic but extreme example of an irrational refusal of life-prolonging treatment. Many negative myths and semi-truths have been propagated about their beliefs. Their desire to cooperate in treatment as fully as their conscience allows is often underplayed. Invariably, such patients have been perceived as a thorn in the flesh of caring health professionals whose aim is to act in the

patient's "best interests" by preserving the patient's life. Undeniably, providing care and treatment in a manner acceptable to the patient's values is frequently a challenge (indeed as it may be in the case of any patient who has a different belief system from that of the health care provider) but it is one which medicine has recently begun to address in a constructive manner by developments in "bloodless surgery".

Two other developments, however, have significantly helped to improve understanding between doctors and Witness patients over recent years. One has been the establishment of hospital liaison committees to work constructively with health professionals and hospital lawyers in the elaboration of clear guidelines about consent and refusal. The other has been the gradual but widespread dismantling of much of the traditional edifice of medical paternalism in favour of an ethic that seeks to involve patients in decision making. A concomitant development has been the growing acceptance that a person's best interests cannot be defined in narrow medical terms but must take account of the whole person — including that person's own wishes and values. Medical treatment is no longer something "done to" patients but rather something in which they participate or not — as full partners. The recent publication by the Royal College of Surgeons of England² of clear and enlightened guidelines serves to emphasise this point. It would be sad if Muramoto's articles, which I consider outside and unwelcome to ethical debate, should undermine the ongoing and constructive dialogue between health professionals and Jehovah's Witnesses.

In this paper I will take forward the scope of this discussion by considering the relationship of rationality to faith. I shall also endeavour to explain the rationale of our position on the use of blood, and why the views of the disaffected should be treated cautiously. I shall offer some layman's opinions on the testing of mental competency and confidentiality.

Patients should make their own decisions assisted by medical information and advice

Autonomy is enhanced when patients are informed. I agree with Savulescu that doctors should be more than "fact providers". The royal college's Code of Practice confirms this approach: "Jehovah's Witnesses are usually well informed both doctrinally and regarding their right to determine their own treatment. It is not the doctor's job to question these principles, but they should discuss with Jehovah's Witness patients the medical consequences of non-transfusion." Madder advises⁵: "Doctors should provide an evaluative judgment of the best medical course of action, but ought to restrict themselves to helping patients to make their own choices rather than making such choices for them".

Within this framework Medical Ethics Today⁶ suggests that a "medical friendship" can develop: "Although emphasis is rightly given to the patient's right of personal autonomy and the doctor's duty to provide adequate information, a further important consideration is the establishment of trust between doctor and patient". From ten years' personal experience working with hospital liaison committees in London and elsewhere, I can confirm that Muramoto is right in believing that the climate between the medical profession and the Witness community is generally friendly and supportive. He finds this position disturbing: I believe that it should be welcomed and approved. I am, however, concerned that by introducing theological debate into medical practice this happy state of affairs could be adversely affected. Savulescu and Momeyer⁷ comment: "As is usually the case, education is better than compulsion". Muramoto may argue that his papers do, in fact, suggest education and not coercion. Readers must judge for themselves. Savulescu and Momeyer put the succinctly8: "Dogmatic ideologues ... show a lamentable propensity to use their 'knowledge' to oppress others, sometimes benignly as paternalists, more often tyrannically as authoritarians. Hence a measure of epistemic scepticism about our own rationality or the lack of rationality in others is highly desirable." All of the above confirm John Stuart Mill's great assertion9: "Each is the proper guardian of his own health, whether bodily or mental and spiritual. Mankind are the greater gainers by suffering each other to live as seems good to themselves, than by compelling each to live as seems good to the rest."

Is the saving of life the most important consideration — rationality and faith!

According to Orr and Genesen¹⁰: "Vitalism" is accepted by a broad spectrum of religious communities and is based on: "The sovereignty of God and the sanctity of human life. Human life is a gift from a sovereign God who has ultimate authority over its beginning and end. Human life is sacred because it was created in God's own image, so that humans are qualitatively different from animals." They argue persuasively on the application of this generally agreed principle. Jehovah's Witnesses agree with the above, and would add that as *The Bible* equates life with blood, then blood is to be regarded as sacred.

However, we do not believe this means that life is the supreme consideration. Neither did Jesus Christ: "The father loves me because I am willing to give up my life. I give it up of my own free will. This is what my father has commanded me to do". And: "This is how we know what love is: Christ gave his life for us". "

The British Medical Journal¹² has examined the German medical profession's cooperation with Hitler in unethical practices. At the Nuremberg Doctors' trials of 1946 some pleaded that their cooperation was effectually coerced by virtue of the implicit threat to their own lives. The examples of Wallenberg, and even Schindler, reveal that individuals are prepared to put their own lives second to their principles. Jehovah's Witnesses will not abandon "love of God" and "love of neighbour" even at the risk of their own lives. Their record in resisting Hitler is well documented, as is the record of the early Christians against the idolatrous Roman emperors. For love of The Bible Tyndale suffered a martyr's death. Can rationality really be evaluated in the same terms as "faith"? The arguments of Savulescu et al omit this essential factor when using Jehovah's Witnesses as the paradigm.

I think it is a mistake to assume that valid decision making can only be made on the basis of short or long term self interest. The Nuremberg judges found they were trying large numbers of pathetic ordinary people who had based their lives on the self-interest principle of staying alive by obeying diabolical orders. Professor King of Staffordshire University finds that Jehovah's Witnesses under the Third Reich took a different line.13 At a recent lecture she said: "The Witnesses were like a rock in mud! In all that slime you had to find something to hold on to, and if it wasn't your own faith, at least here are people who prove that they can do it. These are people who do not spit when the guard's name is mentioned; these are people who deal openly and fairly with all

humanity; these are people you can trust." I hope that there are many things I just would not do (i) because of my own self respect and (ii) because I am convinced that the ways of God are good and pure. Should going this way result in personal benefit then wonderful: but if not perhaps the words of *The Bible*, book of Daniel 3:17–18 are apropos.¹⁴

When in Paris attending the International Symposium of Bloodless Surgery, together with 700 surgeons and health professionals and some dozen Jehovah's Witnesses, I was reminded that the leader of the French Resistance in Lyon refused to divulge the names of his associates to the Gestapo, and died bravely. Was that a rational act? To die for one's moral faith would be viewed by some as irrational. Who is to make a blanket decision on rationality where integrity is more precious to the individual than life itself? To such people betrayal of their integrity is too high a price to pay for life. The plot of Shakespeare's Measure for Measure takes an even deeper look at rationality in the face of life and death. An evil deputy lusts for a pure maid, imprisons her brother on a capital charge and offers the brother's liberty, in return for the willing surrender of her virginity. She says: "O were it but my life, I'd throw it down for your deliverance as frankly as a pin".15 Her life was of less worth to her than her virtue. The brother, under threat of death, takes a different view! At a recent staging I wondered whether the "new morality" would have invalidated the tension of the central moral argument. Happily the modern audience were as outraged at the "Devil's bargain", as earlier audiences had been.

Changes of viewpoint and advance medical directives

Muramoto criticises both our changes in policy on some medical matters and our steadfastness on the refusal of blood - exemplified by the advance directive carried by most adult Jehovah's Witnesses clearly refusing blood even in a lifethreatening emergency. I will deal with these two issues in turn. Since when has changing one's mind been a vice? Having portrayed Jehovah's Witnesses as a group lacking freedom of thought Muramoto rather undermines his case by highlighting their willingness to reconsider and re-evaluate their views in very positive ways. At the time of the first heart transplant by Barnard there was a public outcry from a wide range of religious groups. The British Medical Association (BMA) took some one hundred years to endorse the benefits of vaccination, thus confirming the old adage: "Each good new idea is at first ridiculed, then suppressed and finally accepted as self-evident". Muramoto may come to rue his dismissal of bloodless surgery as a passing fad! Development and flexibility of thought and knowledge are the axiom of rationality. However, we have enthusiastically adopted and promoted advance directives because of our unwavering views on blood transfusions, and our members fully recognise that the advance directives they carry are totally, legally binding.

Advance Statements About Medical Treatment ¹⁶ meets both of Muramoto's objections. "Medical treatment decisions are seldom choices made once for all time, but involve a series of steps as a patient's clinical condition changes and his or her understanding of the real and potential implications develops. Profoundly life-affecting decisions are often [my italics] made against a background of uncertainty, since medicine itself is uncertain and because new techniques are constantly evolving." The BMA can confirm that my religious community has pioneered the use of advance directives. Embryonic British government legislation is seeking ways to extend their use.

Muramoto's examination of the motives of each patient who presents an unambiguous advance directive appears to be an extension of a doctor's responsibilities bordering on hubris. I can see most of our fellowship seizing such opportunities to deliver a detailed lecture about their faith and suggesting that the particular doctor should start to examine his or her own core convictions. Would doctors generally welcome such discussion? Alternatively, would the cause of patient and doctor cooperation be assisted by a terse yet polite reply to "mind your own businessn"! Muramoto argues that these six million advance directives are probably invalid because of alleged "mind-controlling" activities. This deserves specific comment and is addressed below. However, rationality must not be confused with mental competency.

It is a very serious matter for a doctor to question his patients' sanity. Even in cases of obvious mental disorder the High Court has held that a person has capacity to refuse treatment if he understands and retains information relevant to the decision in question, and can assess it in arriving at a choice.¹⁷ What sort of rational reasoning is it that allows a Broadmoor patient with a number of delusions about himself to make a legally valid refusal of treatment, but suggests that one of Jehovah's Witnesses apparently cannot? We now offer an advance directive that includes end-of-life decisions, confirming our rôle as pioneers in promoting ethical medical advances.

Sommerville and Luttrell summarise the debate¹⁸: "It is not necessarily obligatory for an

individual to know each and every one of the risks implicit in a course of action. Indeed if this were the case no person could ever make a valid decision. As human beings, our motivation is often intuitive or emotional as well as cognitive."

Rationale of the Jehovah's Witness position on blood

A recently well publicised case of soldiers from the first world war found in unmarked graves in Belgium and reburied with full honours reveals that life and death are matters on which the vast majority of people have a "deep intuitive moral sense". Proposals to explore the *Titanic* provoked a furore from relatives of the entombed dead. Ancient civilisations identified life with blood, for example, the Aztecs with their open-heart sacrifices, and today the Roman Catholics do so with their daily mass.

The first Biblical mention of blood reveals a metaphysical link with life. Genesis 4:10: "Why have you done this terrible thing? Your brother's blood is crying out to me from the ground, like a voice calling for revenge."19 The occasion, of course, was the murder of Abel by Cain. It would appear that the various blood laws in the Old Testament referred to by Muramoto articulate profound perceptions. Maybe the present controversy about in vitro fertilisation, using sperm from a dead husband, or the cloning of "Dolly" are further aspects of the awe in which life is held. As a Christian I hold that respect for life is part of a natural order stemming from God. Referring to efforts to find life-sustaining synthetic alternatives to blood, Scientific American²⁰ confirms this viewpoint: "It is, after all, the essence of life [my italics] that these investigators, ourselves among them, are trying to understand and manufacture".

One Chronicles 11:17–19²¹ has King David refusing to drink *water* that had been procured at the risk of life. "I could never drink this! It would be like drinking the blood of these men who risked their lives...". Expressions such as "blood money", "blood guilty", "bloodsucker", all reveal this deep association of blood with life. Of course, strict Jewish life even in this modern world is heavily affected by the Kosher laws, as is Islam by the Sharia.

The royal college *Code of Practice* states⁴: "Jehovah's Witnesses have absolutely refused the transfusion of blood and primary blood components *ever since these techniques became universally available*" [my italics]. This is a deeply held "core value". All Witnesses in their public ministry are frequently called upon to explain their faith. Their view on blood transfusions must be defended in situations very far from academic debate.

An interesting example of individual view and action appeared amongst a group of female Jehovah's Witnesses imprisoned in Ravensbruck during the Third Reich. All of the Witnesses refused to make munitions, but diversity arose among them over the matter of making saddles for camels. Some reasoned that these saddles were used for military purposes and so they refused such work. Others reasoned differently. According to one of the women involved,"Refusal to make the saddles brought extreme punishment by starvation and solitary confinement. I realised that I could withstand such treatment ONLY if I was personally convinced of the rightness of my cause. I would have easily broken if I was following someone else's conscience." (Gertrud Poetszinger, personal communication.) They simply agreed to differ. A similar approach is reflected in the attitude of Jehovah's Witnesses to the various blood fractions. Each Witness chooses for himself in these areas. The royal college again⁴: "It is essential to establish the views held by each Jehovah's Witness patient as certain forms of transfusion, such as blood salvage techniques, haemodilution, haemodialysis, cardiopulmonary bypass, and the use of fractions such as albumin, immune globulins and clotting factors may be acceptable". Recent medical advances in the treatment of leukaemia include the harvesting of peripheral stem-cells from the bone marrow prior to chemotherapy and then reinfusing them to give "kick start" to red blood cell production afterwards. Are these stem-cells that develop into blood cells, blood; or are they not? Who is to decide?

Muramoto suggests that work such as I do on the hospital liaison committee consists of ensuring that the membership "toe the party line" - as if there should or could be one in such matters. I find that it is helpful for both health professionals and the Jehovah's Witness patient to have such techniques explained in layman's terms so that the Witness may make his/her own informed decisions. My work, in perhaps the leading heart hospital in the world, which has a record of "bloodless surgery" in the paediatric age group²² has frequently led to a dilemma for parents. The attitude of the surgical team here is that everything possible is done to avoid the use of transfusions in open heart surgery on children and babies, short of allowing death, if in the opinion of the treating team blood could save a life. The parents are not asked to consent to the use of blood, but are encouraged to recognise the situation in law. In effect an attitude of mutual respect and trust has developed. The treating team deal respectfully with the parents' attitude to blood fractions, and

alternative techniques, as mentioned by the royal college.4 But I have frequently found myself explaining that the more restrictions the parents place upon these alternative techniques, the greater the possibility of whole blood or its major components being administered against their will. Each set of parents must be the ones to decide. My role is to help them see the reality of the situation; to give the benefit of my personal experience; to support them; to assist them to make an informed decision. I must emphasise that there is no set of rules whatsoever in this area. Each Witness will give his own personal answers, as is to be expected if the person's individual conscience, and hence that person's personal autonomy, is at work. Savulescu and Momeyer referred²³ in their article to Family Care and Medical Management for Jehovah's Witnesses This is an authoritative practical study, freely available to relevant specialists in medicine, law and ethics on request.

Mind control: reliability of disaffected and anonymous views

Introvigne²⁴ warns of the unreliability and the unrepresentative nature of the views of former members of religious organisations. His authoritative work, which provides material for a further paper, by myself, includes the comment: "It should be clarified that disgruntled apostates, no matter who sponsors their claims, are but a minority of the larger population of ex-members of any given religious minority and should not, without further investigation, be considered as representative of ex-members in general. It is a cause of serious concern that myths discredited and debunked in the USA about brain washing and mind control, thanks to the promotion by the anti-cult lobby, are still taken seriously in certain European countries. They need to be exposed as pseudo-science." Some of Muramoto's anonymous references from alleged dissidents remind me of the Anglia Judaica (1738)²⁵ which is full of horror stories of Jewish "atrocities" against Gentiles at the very time when the Royal Exchequer was in dire need of funds! How easy it is to reinforce prejudices against religious minorities on the flimsiest of evidence. Also how difficult it is to defend and refute a sneer without being guilty of name-calling oneself. For the present surely an "epistemic scepticism" regarding extreme views would be wise. Should any doctors have the time and interest, may I suggest that they compare Muramoto's comments with the mountainous information freely available from their "friendly visiting Jehovah's Witness", or visit Jehovah's Witnesses' official website at www.watchtower.org.

Breach of confidentiality

Disclosure of information is becoming a huge issue in medicine and other disciplines - see, for example, Chambers.26 Briefly I offer a few comments on the "Mary" illustration in the Watchtower article quoted by Muramoto. The complete text (available on request) at very least pictures "Mary" as acting as a free rational individual. I would not have reached the same decision as "Mary". However, "personal relationships sometimes heighten our responsibility to others and may temper the stringency of rules designed to protect our rights and liberties against strangers". 27 It is no doubt difficult for "strangers" to understand the special personal responsibility that Witnesses feel to assist and help one another. These responsibilities are the very evidence of the deep Christian love our community feels. To illustrate, should anyone accidentally discover that a close friend is committing adultery would they be comfortable sharing a meal with the "innocent" partner? I can imagine myself saying to the "guilty" one: "Are you going to tell them or shall I!" Maybe there are no easy solutions to such dilemmas, but for Muramoto to suggest that one article published some ten years ago reveals a network of "informers" trivialises important matters of personal integrity that everyone experiences from time to time. "Loyalty" can be an uncomfortable horse to ride!

Positive aspects of Jehovah's Witnesses' position

Charles H Baron, professor of law²⁸ comments: "The Witnesses have succeeded in showing that blood transfusions, from a purely scientific point of view, are not the completely benign treatment modalities they had been thought to be.... The work of Jehovah's Witnesses to promote bloodless surgery and other bloodless medical techniques has redounded to the benefit of all patients. Their unyielding efforts to promote bloodless medicine through court action and through education and cooperation have benefited all of us. They have earned our thanks."

The clinical risk manager of a leading teaching hospital in London (K Dalby, clincal risk manager, UCH, London, 1996, personal communication) wrote to me recently regarding the successful treatment without blood transfusions of a 29-week preterm baby: "From my point of view, I was very pleased to see such a good relationship based on mutual trust develop between the medical and nursing staff and the parents - I am sure your involvement played no small part in this. Furthermore this successful outcome has made

the paediatricians think again about their routine clinical management of healthy preterm babies."

Comments such as these offered to me freely and frequently make it impossible for me to recognise the picture painted by Muramoto of the religious community of which I am a part. My experience of over 50 years of association has left me with a deep admiration and love for a group of people who have continually found themselves on the outside of current religious, let alone medical, opinion because of their simple adherence to the tenets of Jesus Christ such as "love your enemies", "do good to those who hate you", "go the extra mile" and outstandingly, to preach the good news. Jehovah's Witnesses' record of faith has led them to be adopted as "prisoners of conscience" by such organisations as Amnesty International. Instead of the secretive and closed community imagined by some, we welcome honest examination. Surely few have made greater efforts to educate their membership and the public. The present circulation of our magazine The Watchtower is now over 22 million, in 128 languages! Would it be possible to control the minds of six million people drawn from diverse cultures in 232 countries?

Conclusion

Maybe faith in "whatever" transcends reason, though based upon reason. I think it is sad that holding one's faith has become unfashionable. Pragmatism is now the modern philosophy. Of course, fanaticism, the curse of our present world situation, need not be confused with faith. Without pleading our special faith, the same principle that leads Jehovah's Witnesses to embrace the model of Jesus Christ is the one that motivates them to refuse blood transfusions. Our faith may be labelled as "dotty" by some, but definitely not as "dangerous" to anyone.

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